Patient Perspectives on Spirituality and the Patient-physician Relationship

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OBJECTIVE: To identify the preferences and concerns of seriously ill patients about discussing religious and spiritual beliefs with physicians.

DESIGN: Three focus group discussions with patients who had experienced a recent life-threatening illness. Discussions were audiotaped, transcribed verbatim, and reviewed independently by two investigators to identify discrete comments for grouping into domains. A third investigator adjudicated differences in opinion. Comments were then independently reviewed for relevance and consistency by a health services researcher and a pastoral counselor.

SETTING: Academic medical center.

PARTICIPANTS: Referred sample of 22 patients hospitalized with a recent life-threatening illness.

MEASUREMENTS AND MAIN RESULTS: Almost all of the 562 comments could be grouped into one of five broad domains:

1) religiosity/spirituality, 2) prayer, 3) patient-physician relationship, 4) religious/spiritual conversations, and 5) recommendations to physicians. God, prayer, and spiritual beliefs were often mentioned as sources of comfort, support, and healing. All participants stressed the importance of physician empathy. Willingness to participate in spiritual discussions with doctors was closely tied to the patient-physician relationship. Although divided on the proper context, patients agreed that physicians must have strong interpersonal skills for discussions to be fruitful. Physician-initiated conversation without a strong patient-physician relationship was viewed as inappropriate and as implying a poor prognosis.

CONCLUSION: Religion and spirituality are a source of comfort for many patients. Although not necessarily expecting physicians to discuss spirituality, patients want physicians to ask about coping and support mechanisms. This exploratory study suggests that if patients then disclose the importance of

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spiritual beliefs in their lives, they would like physicians to respect these values.

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 ${f R}$ eligious beliefs and practices are widespread in U.S. society. Ninety-six percent of Americans believe in a divine power, 90% of adults pray at least weekly, and 59% attend worship services at least monthly. Additionally, 58% view religion as "very important" in their lives. 1 Spirituality, a broader term than religion, is defined by categories such as faith, a personal relationship with a transcendent being, a purpose in life, and the ability to find meaning.^{2,3} Illness, because it raises questions of a transcendent nature questions about meaning, value, and relationships—has been described as a spiritual event. 4 To ignore the spiritual aspect of illness, then, is to ignore a significant dimension of the experience.⁵ Yet, spirituality is rarely addressed in medical encounters. 6,7 For centuries medicine was a profession tending to both body and spirit.8 William Osler, still viewed as the preeminent physician of modern times, 9-11 was regarded as a great physician in part because he addressed patients' spiritual needs. 12,13 While patients often still view doctors as "secular priests," 14 most contemporary physicians do not see it as their role to care for patients' spirits. 13,15

Spiritual beliefs serve as a source of guidance^{16,17} and coping^{18–20} for many people facing serious illness.²¹ Consequently, many have commented on the need for physicians to be more sensitive to patients' spiritual needs.^{22–24} While several studies indicate that physicians realize the importance of spirituality,^{25–27} they disagree on its role in the physician–patient relationship.^{28,29}

Given the uncertainty about how to integrate this information into clinical practice, we were interested in patients' perceptions of whether and how physicians might best address these issues. We hypothesized that many people with serious illness may want their spiritual beliefs acknowledged in some way. However, we did not want conclusions influenced by our assumptions so we sought a patient-centered approach, one that is congruent with patients' needs, values, and attitudes. Focus groups provide an effective means of exploring people's needs and attitudes. By utilizing group process, they capitalize on the communication between participants, allowing them to use their own language to describe issues they find important.

METHODS

Sample

We recruited English-speaking patients 18 years of age or older who had experienced a life-threatening illness in the 12 months prior to conduct of the focus groups. Because of their illnesses, these individuals were likely to have reflected on their spiritual beliefs. Additionally, because of their interactions with many health care professionals, they had multiple experiences upon which to evaluate their preferences for spiritual and/or religious discussion.

We sent faculty physicians letters asking for assistance in finding participants. Disciplines included general medicine, cardiology, endocrinology, nephrology, and general, cardiovascular, and surgical oncology. Physicians were asked to recruit patients without regard to religious or spiritual orientation. Patients were recruited by their physicians with a letter describing the study and inviting their participation. The letter stressed that participation was voluntary and that medical care would not be affected by their decision. Patients who agreed to participate were then called by one of the investigators. The Johns Hopkins institutional review board approved the study.

Conduct of Focus Groups

A trained moderator (MWJ) conducted three focus groups, each consisting of 6 to 8 patients and lasting approximately 90 minutes. The three focus groups were conducted in July 1999 and June 2000. No study physicians were present during the sessions. We provided free parking, light refreshments, and a \$20 honorarium to cover travel and childcare expenses. Discussions were audiotaped and transcribed verbatim.

Additional Data Collection

Patients completed a brief questionnaire assessing demographic characteristics and spiritual beliefs and practices. We provided participants with definitions of religion and spirituality to facilitate discussion and prevent confusion. Religion was defined as participating in organized religious activities (such as church, synagogue, temple or mosque services), holding specific traditional religious beliefs and perspectives, and/or following a specific religion's teachings and practices. Spirituality was defined as believing in the existence of a power greater than oneself, believing that life has purpose and meaning, and/or having a relationship with a higher power. To be spiritual did not require one to be religious. Each focus group session then began with six open-ended questions followed by specific probes (Table 1).

Data Analysis

Content analysis was performed on transcripts. 36 Two authors (RSH, MWJ) independently identified all relevant

Table 1. Focus-group Questions

- 1. What are the most important aspects of spirituality or religiosity for you?
- 2. Have you ever discussed your spiritual or religious beliefs with your doctor or other health care professional?
- 3. Were there times you would have liked to discuss spiritual beliefs or practices with health professionals but did not?
- 4. What aspects of your religious or spiritual activities would you like to discuss with your doctor?
- 5. How and when could doctors treating you incorporate your religious or spiritual beliefs into your treatment?
- 6. What would be the one thing you could tell doctors about your religious beliefs and practices and your health/illness that you think they do not realize?

comments from the transcripts and grouped 562 comments into domains and subdomains. Repeated or reworded comments of the same thought by the same participant were counted once. Data collected from the first 2 focus groups was analyzed prior to conduct of the third. Consensus on the final taxonomy was sought through domain saturation, i.e., by noticing which domains persistently emerged from the data.³⁷ A third investigator (LAC) experienced in focus group methodology adjudicated any differences. A physician/health services researcher (DEF) and a clinical social worker with training in pastoral counseling (DRO) then checked groups of comments and domains for relevance and consistency. Focus group participants were given the final taxonomy for review and comment.

RESULTS

Focus group participants had been hospitalized for a variety of conditions including cancer (n = 11), end-stage renal disease (n = 5), coronary artery disease (n = 4), diabetes mellitus (n = 4), and systemic lupus erythematosus (n = 1). Some patients had more than one condition. All participants were of Judeo-Christian faith; most were married, had attended college, and had a self-reported health status of good or better. While the majority of participants thought religion or spirituality was at least somewhat important in their lives, their seeking of spiritual support and/or frequency of prayer was varied (Table 2).

Almost all topic-specific comments were categorized into five broad domains: 1) religiosity/spirituality, 2) prayer, 3) patient-physician relationship, 4) religious/spiritual conversations, and 5) recommendations to physicians. These domains contained a number of subdomains, presented in Table 3, which are discussed below.

Religiosity/Spirituality

Thirty percent of comments pertained to religiosity and/or spirituality; subdomains included manifestations of religiosity/spirituality, the interconnectedness of

Table 2. Characteristics of Study Sample $(N = 22)^*$

Patients' demographics, n	
Age	
25-39	3
40-64	9
65+	10
Gender	
Female	11
Race	
African American	9
White	13
Marital status	
Married	14
Separated/divorced	3
Widowed/never married	5
Educational level	
<high school<="" td=""><td>1</td></high>	1
GED/High school	4
College	17
Self-reported health status	
Excellent/very good	11
Good	8
Fair/poor	3
Patients' spiritual status, n	
Affiliated with a religion	
Yes	17
No	3
"I am a religious person"	
Strongly disagree/disagree	3
No opinion	3
Agree/strongly agree	14
"I am a spiritual person"	
No opinion	4
Agree/strongly agree	17
"How often do you pray?"	
<once a="" td="" week<=""><td>4</td></once>	4
Several times a week	2
≥Once a day	15
Importance of spirituality	
Not at all/not very	2
Somewhat	6
Very	13

^{*} N not always equal to 22 secondary to patient nonresponse.

religiosity/spirituality, maintenance of spirituality in the setting of illness, and God/Holy Spirit. Participants described religion in terms of church attendance, ideologic involvement, and fellowship:

I needed to be a part of the Church rather than just a member, so I've decided to teach Sunday school. —53-year-old African-American male

Spirituality was described in broad terms such as faith, reflection, healing, meaning, hope, and purpose:

...reflect on what's happened to me and how that fits together with some higher being. —35-year-old white female

Whereas most patients described themselves as religious and/or spiritual, a few did not. Some participants raised questions of an existential nature by questioning the meaning of their illness and how it might fit into a "big

picture." They wondered why, in light of their faith, they got sick:

 \ldots why did this happen to you, you go to Church \ldots — 58-year-old African-American female

For some, the introspection caused by illness led to an increase in spirituality:

I became more amazed by the trees and birds, ducks, the wonders of nature. — 35-year-old white male

People who admitted questioning their faith during illness were able to resolve their doubts without loss of faith

God was often mentioned as a source of comfort, guidance, and healing. Faith gave respondents the strength and emotional support necessary to cope:

...cause I have complications from diabetes and I don't think I could make it if it weren't for my faith and strength and getting that from God. — 52-year-old white female

For these discussants, the idea that God would not abandon them was a thread that wove itself throughout their comments:

God's in everything you do.—40-year-old African-American female

Some respondents perceived God's involvement in guiding the physician. The physician was viewed as a vehicle through whom God operates:

...you're going to pray to God and ask the Lord to guide His surgeon's hand, show him what he should be doing...—58-year-old African-American female

Prayer

Prayer in times of illness and/or health was very important for many patients as a source of comfort, support, and guidance:

I prays [sic] all the time...sometimes the answers come right in front of me. —48-year-old African-American female

Many patients attributed their improvement to prayer.

 \dots Lord began to put weight back on my body and brought me through that. — 58-year-old African-American female

Some respondents believed that prayer and faith could cure their illness:

My children felt it was a mistake to go, visit a faith healer. They don't believe in this but I want to tell you something, it worked. I couldn't have done it, gotten cured, without her. -68-year-old white female

This belief was so strong that they implied they might no longer need conventional medical care:

I received the Spirit...and I believe God healed me through prayer last Sunday. When I go see my rheumatologist, I'm going to tell her that her tests are going to come back negative. The only thing I have to do now is get weaned off all this medicine. — 40-year-old African-American female

Table 3. Focus Group Taxonomy

	Commont (0/)
	Comments, n (%)
I. Religiosity/spirituality	171 (30)
Manifestations of religion	
Manifestations of spirituality	
Interconnectedness of religion	
and spirituality	
Maintenance of spirituality	
in the setting of illness	
God/Holy Spirit	4
II. Prayer	69 (12)
In time of need	
Intercessory prayer	
Projected responses to prayer	
in the health care setting	100 (10)
III. Patient-physician relationship*	102 (18)
Interpersonal skills	
Socio-emotional support/	
"bedside manner" Comfort/confidence	
Faith	
Hope Ethics	
Equation of strong interpersonal	
skills with spirituality	
Taking a personal interest in patients	
Patient-physician communication	
Willing to leave a physician with	
poor communication skills	
Technical skills	
IV. Religious/spiritual conversations*	190 (34)
Integrated into the medical context	` ,
Barriers to the discussion	
Entry points to the discussion	
Projected responses to physicians'	
refusal to acknowledge spirituality	
Discussion with nonphysicians	
Separate from the medical context	
Negative aspects of physician	
discussion of spirituality	
No strong opinions	
Context for spirituality-	
oriented conversation	
Illness related	
Non–illness related	4-1
V. Recommendations to physicians	26 (5)
Acknowledgement of	
spirituality's importance	
Be sincere with the discussion	
Refer patients for spiritual counseling	
Discussion of prayer	4 (1)
VI. Other	4 (1)

^{*} Domains III–V include aspects of patient-physician interaction and are presented in full. Complete taxonomy available upon request.

In addition to individual prayer, intercessory prayer by and for others provided informants with an intimate sense of connection. Patients were comforted by the knowledge that people were praying for them.

I had people across the country praying for me...putting my name in their prayer list at church... — 52-year-old white female

Some patients prayed for their physicians:

What if you were having surgery and told your doctor, "I'm going to say a prayer for you tonight for you doing the operation"...—35-year-old white female

People made many comments about prayer in the health care setting. Most indicated receptiveness to discussion with physicians or clergy:

...would have liked if my doctors had been in prayer with my family and minister and I before my operation. — 52-year-old white female

In fact, some said that a physician's refusal of their request for prayer would result in their seeking care elsewhere:

I shouldn't have asked for prayerMaybe this person is not the one for me...find somebody else. — 42-year-old African-American female

Patient-Physician Relationship

A large number of comments pertained to the patient-physician relationship, independent of discussions about spirituality. Dialogue about interpersonal skills, communication, and "bedside manner" was prominent.

A long-term patient-physician relationship, while necessary, was not sufficient for patients to feel comforted by their physician:

...I would have to build a relationship with him, the physician, to feel that way, because I've had quite a few physicians for a period of time, but I didn't feel that way. — 40-year-old African-American female

Physicians who, through their actions and words, respected patients' individuality and fostered an environment based on mutual respect and interest were most likely to generate comfort and confidence:

There are things that they communicated and the manner in which they did it. It developed a tremendous amount of trust and confidence between both individuals, patient and physician.—74-year-old African-American male

Although physicians were not asked about their belief systems, patients viewed physicians who generated confidence as spiritual:

I've always felt the spiritual part. We didn't talk about it, but we didn't have to. I just had confidence in him, and it, the spiritual part, was there for me. — 74-year-old white male

Disappointment in physicians' interpersonal skill would lead some patients to change physicians.

Religious/Spiritual Conversations

Patients were divided as to whether spiritualityoriented dialog should be a part of medical practice. For patients in favor of dialog, tending to patients' spiritual needs was viewed as integral to medical care. The discussions alleviated some of the illness burden:

I think it, spirituality-oriented conversation, could ultimately make you feel a lot better. It's never the cancer that bothers you, it's the tension and anxiety of having it. -34-year-old white male

The most frequently mentioned barrier to spiritualityoriented conversation was patients' perception that physicians were either not interested or too busy:

They don't have enough time. You gotta try to get all this in about a half an hour. — 67-year-old African-American female

For these reasons, such patients preferred to discuss their beliefs with nurses:

Nurses have more time with the patient than the doctor. You get to know a nurse a lot better than a doctor. -68-year-old white female

Other barriers included the thought that physicians were prohibited from discussing religion, fear of offending someone of a different faith, and viewing physicians as lacking sufficient training for such a discussion.

Participants reported that all barriers to this discussion could easily be overcome if physicians allowed spirituality-oriented discussions to evolve from psychosocial inquiry:

They could ask you how comfortable you feel, if you feel stressed out, and what would help you. That would open up the opportunity to bring it, spirituality, up in the conversation. -52-year-old white female

Another entry point mentioned was to approach the topic around religious holidays.

It was one of her holidays, Jewish holidays, and I was asking her the doctor, what was she gonna do, and she said we have seven days, it must be Christmas, for seven days, and she was telling me, "Well, what are you going to do?" I said we have this affair at church. Then we started talking. — 67-year-old African-American female

Spirituality-oriented discussion may lead to patientdirected questions about physicians' religious or spiritual practices:

That would be comforting to me to know if my doctor prays. -34-year-old African-American male

Patients did not expect physicians to reveal personal beliefs if it made them uncomfortable. They did, however, expect physicians to be sincere with any conversation, regardless of whether they revealed their beliefs:

...you don't want him to be a fake. — 35-year-old white male

A few patients preferred talking to clergy rather than medical personnel:

I doubt that I would be in a position or feel like discussing it with the doctor. I'd rather go to this Orthodox Christian priest. — 74-year-old white male

Some patients did not want spiritual issues discussed. Reasons included the fear that doctors would impose their beliefs and the perceived implication that any physician mention of spirituality, religion, or prayer during time of illness suggests a poor outcome:

Any doctor who would approach me and start talking about religion right now, I'd think, oh, boy, I've got something really wrong. — 77-year-old white male

Several comments reflected the view that these deleterious effects were most likely to occur if the discussion was not expected:

Then, all of a sudden, if they're bringing this up and telling you...it's making you wonder, okay, what do you know that I don't... And that's a little intimidating. — 52-year-old white female

Some participants initially had no strong opinions on the topic:

If he wants to deviate and find out what my religion is or what my faith is and we want to discuss it, it would probably be a one-on-one discussion with no problem.—74-year-old white male

Interestingly, these patients changed their minds during group discourse. Upon participating in the discussion, they thought that conversation about spirituality, flowing from psychosocial history taking, would be welcomed.

Participants were divided as to the appropriate context for dialog on spiritual matters. Some thought the proper setting was major illness. For them, this was the time when spirituality came to the forefront:

I'm thinking of life-threatening operations...life in their hands. — 74-year-old white male

Others preferred to incorporate spiritual issues in the course of routine medical care or screening:

There is a lot of room for that, physician discussion of spirituality, and not make it like the grim reaper—turn it into a positive opportunity. -35-year-old white female

Recommendations to Physicians

In closing, we asked patients to make recommendations to physicians. All patients wanted doctors to discuss coping mechanisms and show empathy. Participants wanted physicians to acknowledge that spirituality and religion are important for many patients. If spirituality-centered talk evolved from psychosocial inquiry, participants wanted the topic treated with respect.

The acknowledgment would be nice.... I believe in a spiritually higher power...acknowledge it, in a very sincere way...it could ultimately make you feel better.—34-year-old white male

If physicians feel uncomfortable, patients recommended that their needs be met by referral to clergy:

They could sit and talk to you about it, spirituality, and if they didn't, they could say, "Well, I will get someone to talk to you." -49-year-old white male

A few patients requested that their physicians pray with them:

...addressing it, prayer, without overstepping, without imposing anything on them, patients. You doctors can address it with, "Would you like that?" for a doctor to pray with the patient. "Would that comfort you?"—52-year-old white female

DISCUSSION

Our results demonstrate that patients see the role of spirituality in medical encounters as closely tied to the interpersonal relationship and the psychosocial care provided by physicians. Physicians need strong interpersonal skills and a well-developed relationship with their patients prior to discussion of spirituality. If these do not exist, a dialog may be offensive and possibly harmful. Participants were not expecting physicians to initiate or pursue spiritually oriented dialog. They also did not want physicians to prescribe or dictate religious behavior. Rather, all wanted physicians to inquire about social support and coping. This line of questioning would leave the avenue open for those patients who want to discuss spirituality.

Surveys have shown that patients are divided as to whether they want spiritual dialog with physicians. ^{7,38–40} Our findings substantiate this while providing clarification and insight about why patients may or may not want this dialog. Regardless of their thoughts on spirituality, our patients all expressed the need for communication and exchange with their physicians. This sentiment may partially reflect the fact that the chronically ill are at risk for poor communication. ⁴¹ Encouraging open dialog affects patients' decisions to continue the physician-patient relationship, ^{42–45} is an important component of healing, ⁴⁶ and generally enhances the patient-physician relationship. ⁴⁷

Barriers exist to incorporating discussions of a spiritual nature. Physicians traditionally receive little training in addressing patients' psychosocial needs. 48 Doctors have also expressed concerns about role uncertainty, difficulty in identifying patients who want to discuss these issues, concerns about projecting beliefs onto patients, and time constraints^{25,26}—concerns similar to those expressed by our patients. However, a physician need not be religious to recognize the importance of spirituality. Because our patients' perceptions of spiritual care depended on behaviors such as active listening, availability, and understanding, good spiritual care can be provided without shared beliefs. 49,50 In addition, studies have shown that exploring psychosocial issues does not necessarily translate into longer visits. 51,52 Finally, patientdirected questions about their physician's faith beliefs may make some physicians uncomfortable. Patients were cognizant of this fact. In such instances, patients said referral to clergy was appropriate. Trained chaplains can

be helpful when spiritual topics fall outside a physician's competence or comfort. 53

Our study has several limitations. First, focus groups are useful for identifying major domains, but the qualitative nature of the data dictates caution in analysis of subtle subdomains. Review of the data is subject to personal interpretation; and many of the subdomains and comments are not mutually exclusive. However, surveys themselves are not without limitations as patients' responses can be heavily influenced by the way this subject is introduced and the manner in which survey questions are worded. 40 Second, because focus group discussions consist of small, relatively homogeneous groups of people, selection bias may be an issue. The viewpoints of our participants may differ from those of individuals with similar illnesses who were never recruited. Our focus group participants may have provided a narrow range of input. The participants had a relatively high educational level and did not include many ethnic minorities or religious affiliations. Also, because our participants were recruited from one geographic area, they may not be representative of the country as a whole. Focus group participants, however, are generally selected to generate a wide spectrum of viewpoints and to provide in-depth information that can be used for hypothesis generation for future research. 33,54 While our study is hypothesis-generating, more work is needed to further characterize discussions of a spiritual nature with physicians. The comments and viewpoints proposed by our participants suggest that the representation was broad if not comprehensive. Third, because our participants had experienced recent life-threatening illness, their perspectives may not reflect those of healthy outpatients. Fourth, the possibility of response bias exists. Some participants may have had concerns about confidentiality or not been at ease relaying their true feelings. For example, the participants who initially had no strong opinion on spirituality-oriented conversation with physicians changed their minds in the course of group discourse. While this may represent peer group-mediated shift, it may also reflect group work facilitating discussion, with less inhibited members encouraging the participation of shyer informants. 32 The level of participation and the breadth of comments generated by their discussions make response bias unlikely. Our system of having investigators from multiple disciplines analyze the data at different steps minimized investigator bias. Furthermore, we asked focus group participants to review the taxonomy; those who responded (N = 12) thought it was an adequate representation of their group's discussion.

What are the implications of this study for medical research and clinical practice? Our study suggests that research into patients' needs for spiritual care should incorporate general measures of the quality of patient-physician communication and the strength of the patient-physician relationship. Also, prior to incorporating curricula^{55–58} or using available guides for spiritual

assessment, ^{59–61} physicians need to have competence in communication skills and develop a relationship with the patient. Physicians should also realize that religious beliefs might sometimes lead to maladaptive coping mechanisms ⁶² such as believing that conventional medical care is no longer needed. Clergy are available and can be helpful in such situations. ^{14,63} Finally, what was not said in the focus groups is interesting. Nobody made mention of issues such as organ donation, end-of-life care, or advance directives. Given that these topics often have religious significance, ^{17,64,65} more research is necessary to determine how physicians may best address these issues.

Physicians have an obligation to provide the best possible care to their patients. Our exploratory study suggests that this may include acknowledging the role of spirituality for many patients. As physicians respectfully explore religiosity/spirituality with those patients who desire it, a deepening of the therapeutic alliance may lead to more effective care.

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